

Stigma and safe havens: A medical sociological perspective on African-American female epilepsy patients

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Abstract

Purpose. Very little is known about the attitudes and behaviors of minorities with epilepsy. This pilot study explored access to health care, help-seeking behaviors, and adherence to treatment among African-American females with epilepsy.

Methods. Ethnographic interviews were conducted with 10 African-American female adults.

Results. Findings indicate four major obstacles to care: limited financial resources, lack of knowledge about epilepsy among African-Americans, poor patient–provider communication, and lack of social support. Social support impacted individuals seeking surgery, and also affected purchasing medication, adherence to medical treatment, and needed transportation. Lack of knowledge and misinformation about epilepsy in the African-American community and poor communication with physicians contribute to the social stigma felt by these patients.

Conclusions. The behavioral epidemiology of epilepsy among African-Americans is lacking. This disease exacerbates health disparities for this population. These findings point to a need for a safe haven for these individuals.

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1. Introduction

The National Institutes of Health defines health disparities as the “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States” [1]. A large body of literature has documented significant racial and ethnic disparities in access to health care and health outcomes, with minority Americans generally receiving less health care and suffering worse health [1,2]. Reducing health disparities among different racial and ethnic groups and socio-

economic levels in the United States leads to improved health and is a responsibility of all health care providers and public health practitioners [3].

Like many other health conditions that are overly represented in minority populations (e.g., heart disease, cancer, diabetes, HIV/AIDS) [1,4], significant health disparities exist among epilepsy patients [4]. Even though epilepsy is a condition that affects people of all races, ages, and various socioeconomic levels, research indicates that minorities are disproportionately affected by this condition. The number of epilepsy patients per 1000 persons among African-Americans under age 45 is 6.1, compared with 4.3 among whites [4]. Minority groups face substantial barriers to care such as language and communication barriers, medical practices that differ from their own

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beliefs and traditions, fear and mistrust of health care institutions, and a lack of knowledge about how to navigate the system [3]. These sociocultural barriers can then lead to difficulties in scheduling appointments, misunderstandings between clinicians and patients, misdiagnoses, and low adherence to treatment [3,5].

Epilepsy disparities also exist with respect to income and education. Persons of low socioeconomic status, often in minority communities, are at greater risk for epilepsy. The incidence of epilepsy among individuals aged 45 years and younger and having an annual family income of less than \$10,000 is 13.2 per 1000. However, the incidence rate for the same age group with an annual family income of \$35,000 or more is only 3.0 per 1000 [4]. Furthermore, a subsample of adults with epilepsy in one study (2.1% among the sample of 8057 adults) had lower educational attainment and lower household incomes [6]. The 2002 study also found that among individuals with various health problems, those with epilepsy reported significantly worse health status compared with those without epilepsy [6]. A study in 2000 by Fisher et al. revealed similar findings [7].

The reasons for these differences in the incidence of epilepsy have not been identified [8]. Furthermore, researchers do not know whether epilepsy among poor minorities is due to racial variations or socioeconomic factors [8,9]. Additionally, minorities and low socioeconomic groups might be at greater risk for epilepsy in the United States because they have higher incidences of seizure risk factors such as stroke [8,10], diabetes [4,11], and hypertension [4,10].

In addition to income and racial and ethnic disparities, regional disparities also influence the prevalence and incidence of epilepsy. Nationally, the prevalence of epilepsy is estimated to be 0.5 to 0.8% , with approximately 181,000 new cases being diagnosed each year [4]. However, the Midwest has the highest rate of epilepsy, with 7.9 cases per 1000 [4]. In comparison, the Northeast, South, and West register at 4.4, 3.7, and 4.6 cases per 1000, respectively. Locally, where the current study took place, there are 13,000–21,000 cases in Kansas and 3000–5000 in Sedgwick County [4].

The majority of previous literature has focused on the perspectives of medical care professionals, while few have considered the voices of the patients themselves [7,12–15]. The majority of studies that have focused on patients' perspectives have been internationally based [16–21], although some exceptions exist [22–26]. The Brainstorm Series has produced three books [24–26] that provide personal accounts of American patients' experiences with epilepsy, including *The Brainstorms Woman: Epilepsy in Our Lives* [24], which is a compilation of stories told by women with epilepsy. While these books provide insight into the individual and interpersonal aspects of seizures and epilepsy, they do not focus on these experiences from a racial and ethnic perspective or from

the standpoint of how researchers and practitioners can use the information to generate studies or institute improved services, projects, and practices.

Applied studies that investigate the perceptions and experiences of minority epilepsy patients and translate findings into meaningful action to reduce health disparities for epilepsy treatment are needed. At present, very little is known about the attitudes and behaviors of minorities with epilepsy [12], and even less is known about the factors that influence them. The information obtained from the current study is critical to fulfilling this gap in the literature and might better guide health researchers, physicians, and other health care professionals in their study and treatment of epilepsy among minority patients. Additionally, such findings can serve to guide initiatives such as those by the National Institute of Neurological Disorders and Stroke (*Reducing Disparities in the Treatment of Epilepsy*) [18], and others.

The catchment area for the present study was the Midwest, specifically, Wichita, KS, USA. More Kansans live in Wichita than any other community in the state, and the city is one of the most racially and ethnically diverse [27]. Approximately 75% of the city's population is non-Hispanic white (identical to 75% nationally), with 11% black or African-American (12% nationally) and 10% Hispanic or Latino (13% nationally) [27]. The median household income for Wichita is \$39,939 (compared with \$41,994 nationally). Overall, educational levels for the city are also comparable to national statistics; approximately 84% of the citizens are high school graduates or higher (compared with 80% nationally), and about 25% have bachelor degrees or higher (compared with 24% nationally) [27].

2. Methods

The purpose of this qualitative study was to investigate by in-depth interviews the knowledge, attitudes, and beliefs associated with epilepsy among African-American patients. Moreover, factors contributing to insufficient access to health care, inadequate help-seeking behaviors, and low adherence to treatment among African-American epilepsy patients were assessed. To this end, the following research questions were explored: (1) What are the perceived barriers or factors that are associated with obtaining adequate medical attention for epilepsy? (2) What factors influence their care-seeking behaviors? (3) What factors influence adherence to treatment? (4) What are their recommendations for potential solutions to the above problems?

2.1. Sample

To serve as a catalyst to stimulate further research, this pilot study consisted of ethnographic interviews

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